

THE HEALTH-RELATED QUALITY OF LIFE IN MOTHERS OF SURVIVING DEAF BLIND ADULT CHILDREN WITH CONGENITAL RUBELLA SYNDROME IN THE UNITED STATES

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Abstract

The purpose of this study was to determine the health related quality of life (HRQOL) of mothers of surviving deaf-blind adult children with congenital rubella syndrome (CRS) and the relationship of factors that influence it. This study uses a cross sectional design with all of the study participants having surviving CRS children born from the 1963-1965 epidemic.

Analysis revealed: 1). Maternal CSI scores were significantly associated with the HRQOL $F(13, 273) = 67.175$ $p < .001$. Mothers who experienced high levels of caregiver stress had a poorer overall quality of life than those with lower levels of stress. 2). The deaf-blind adult child's with CRS functional ability was significantly associated with the maternal HRQOL $F(22, 263) = 17.03$ $p < .001$. Mothers of adult deaf blind children needing care had poorer overall quality of life than those more independent. 3). Communication methods were significantly associated with the HRQOL. Communication with Sign Language ($M = 80.39$, $SD = 20.8$) demonstrated better overall maternal HRQOL scores than those with gestures ($M = 31.49$, $SD = 32.57$), $F(8, 277) = 17.471$, $p < .001$. 4). Behaviors were significantly associated with the HRQOL with the largest difference between adult- children demonstrating no apparent behavior ($M = 89.77$, $SD = 11.7$) to those presenting aggressive behavior ($M = 30.95$, $SD = 30.37$), $F(7, 279) = 21.130$ $p < .001$. As the prevalence of children with disabilities continues to increase, so does the demand for professionals who understand the unique needs of caregivers. Professionals must understand the impact special needs have on the mother and by extension, the family, and be able to provide the care and resources needed to support the continued care.

Keywords: Congenital Rubella Syndrome, Deaf blind, Health, Mothers

Introduction

Today, there is increasing discussion of the need to not only assess, monitor, and cure specific disorders but also to consider a larger concept referred to as the health related quality of life (HRQOL) (Franic & Bothe, 2008). There is no single agreed-upon definition of HRQOL, although there is at least a consensus that it is dynamic and multidimensional. Definitions include "the value assigned to the duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy" (Patrick & Erickson, 1993, p. 22), as well as "patients' perceptions of performance in four areas, physical and occupational, psychological, social function and somatic sensation" (Bergner, 1989; MacKeigan & Pathak, 1992; McHorney & Tarlov, 1995; Patrick & Erickson, 1993; Schipper, Clinch, & Olweny, 1996, p. 11). However, the current standard is to view HRQOL as encompassing four domains: physical functioning, social functioning, role functioning, and mental health (Bergner, 1989; MacKeigan & Pathak, 1992; McHorney & Tarlov, 1995; Patrick & Bergner, 1990). Hence, HRQOL focuses on how the person feels, as opposed to clinical test results (Clancy & Eisenberg, 1998).

Studies have indicated that taking care of children with disabilities is often associated with impaired parental physical, social, role and mental functioning (Dyson, 1997; Hedov, et al, 2000) with mothers experiencing most of the negative effects (Beckman, 1995; Bristol, et al, 1988; Dyson, 1991, 1997; Hedov, et al, 2000; Krauss, 1993; Trute, et al, 1995). Terms such as caregiver burden and caregiver strain are commonly used to capture the negative consequences of undertaking this caregiving role (Hunt, 2003).

Smith (1996) identified a number of caregiver stressors, including demanding physical care of the individual, management of household and financial affairs, and direct observation of worsening conditions. Other variables observed included limited social lives, loss of privacy, sleep disruption, curtailed activities of other family members and generalized family dysfunction (Smith, 1996).

In 1962, a pandemic of German Measles (rubella) occurred, starting in Europe and later spreading to the United States. Between 1963 and 1965, the United States reported 12.5 million cases of the virus which gave rise to 20,000 cases of the congenital syndrome, including approximately 6,200 stillbirths (Herrmann, 1991). Rubella is generally benign to children and adults who contract it. However, it causes serious and lifelong health problems in the offspring when their mothers develop this disease during the first trimester of pregnancy. Infants of infected pregnancies are born with ocular, auditory, and other systemic abnormalities which are common manifestations of congenital rubella syndrome (CRS). Between 1963 and 1965 an estimated 20,000 infants were born in the United States with

congenital birth defects caused by the rubella virus (Herrmann, 1991). Many of these babies were born deaf, with vision problems and mental retardation. Today, this surviving CRS population, now adult, has unique problems with communication, mobility and other daily living skills that make independent living more difficult to achieve. Additionally, many residential services have little or no experience providing the supports needed by adults who are deaf-blind which often leaves the immediate family to care for them.

The cost associated with long-term care of individuals with CRS represents an economic burden for affected families and for society with an estimated cost of \$514,000 per case (PHAC, 2002). This figure does not reflect the additional financial burden surrounding the health of the primary caregivers, in particular, as it relates to the well-being of the mothers.

If the results of this study are consistent with results involving other disabled populations which demonstrate a negative effect on the health of the mother, it will support the need for earlier and more comprehensive services for families of individuals with CRS. Additionally, these results may illuminate the needs of other children with similarly severe disabilities.

I.

Purpose

The purpose of this study is to determine the health related quality of life (HRQOL) of mothers of deaf-blind adult children with congenital rubella syndrome (CRS).

- * This study examines both internal and external factors related to mothers of deaf-blind adult children with CRS.

- * Internal factors are those unique to the care of the deaf-blind adult with CRS including: method of communication; behavior; functional ability and maternal caregiver strain.

- * External factors, those which the literature has found to influence a HRQOL, include: the residential status of the deaf-blind adult child with CRS; the utilization of services; maternal financial status and education.

Literature review

Research has identified a number of caregiver stressors, including demanding physical care of the individual, management of household and financial affairs, and direct observation of worsening conditions. Other problems observed included limited social lives, loss of privacy, sleep disruption and curtailed activities of other family members (Townsend & Davidson, 1992).

The literature indicates a major factor contributing to caregiver strain and the caregiver's HRQOL is communication difficulty between the

caregiver and the person needing care (Kreps & O'Hair, 1995; Query & Kreps, 1996).

Research suggests that parental HRQOL is directly correlated with child behavior and mothers who provide care for adult children with mental disabilities have higher rates of chronic health conditions (Allik, et al., 2006; Magaña, et al., 2004).

Caregivers who care for impaired individuals report significantly higher caregiver strain scores than do caregivers who provide care to healthy individuals. Additionally, as the dependency increases, caregivers report poorer perceived health, increased health-risk behaviors, and increased anxiety and depression (England, 1996; England & Roberts, 2000).

Knowledge Gaps

It is not fully understood why some caregivers experience changes in their HRQOL and others do not. There are inconsistencies in the area of caregiver research; however, maternal HRQOL is underrepresented in the literature. Although considerable attention has been directed toward caregivers of acute and chronically ill individuals, there is limited information specific to those who care for the developmentally disabled population and no identified research on the care of adult children with CRS. Predictors of maternal HRQOL need to be defined in order to potentially promote health for these mothers and insure adequate, cost effective and appropriate health care for this population. Additionally, the pattern of support services used by these caregivers has not been investigated as well as their expectations of and barriers to using services.

Method and Design

This study uses a cross sectional design. Implicit in the cross-sectional study is the assumption that the study population has been exposed for a long time and will continue to be exposed unless some intervention is affected. All of the study participants have surviving CRS adult children born from the 1963-1965 epidemic. The dependent variable assessed is the maternal HRQOL represented by the eight domains within the SF-36. Independent variables assessed are divided into main predictors (internal factors) and covariates (external factors).

These include: years of maternal caregiving, adult deaf-blind child's residential status, maternal marital status, number of children, maternal education, maternal caregiver strain, method of communication, adult deaf-blind child's behavior, utilization of services, adult deaf-blind child's functional ability and maternal financial status. In addition, to ascertain the qualitative aspects of parenting an adult child with CRS and to assess

correlation of verbal and written responses, 5% of the study sample was contacted via phone interview.

Participants

This investigation focuses exclusively on the mothers of surviving CRS adult children born as a result of the 1963-1965 epidemic as its case criteria. According to HKNC's national registry, there are approximately 1000 deaf blind individuals 21 and older who are listed as having CRS in the United States (HKNC, 2006). According to the CDC, this cohort is the result of the 1963- 1965 rubella epidemic.

Data Collection Method

In this study, Helen Keller National Center's (HKNC) national registry was used to identify mothers who fit the case criteria (having a child with CRS from the 1963-65 epidemic). Mothers of deaf-blind adult children with CRS identified by the registry and who fit the case criteria were asked to participate in this study, via mailing, by the executive director of the HKNC. In addition public announcements were made by the National Rubella Listserv website.

Sample size and power analysis

An a-priori power analysis was conducted to determine the number of participants required to detect a medium effect size with power = .80 for a sample at alpha = .05. The power analysis suggested that 286 participants would be needed to achieve a power of .80 (<http://www.danielsoper.com/statcalc/calc16.aspx>).

Data Collection Tools

Demographic information was incorporated into a self -administered maternal questionnaire.

In addition, mothers of adult deaf-blind children with CRS were asked to complete: the Medical

Outcomes Study 36-Item Short-Form Health Survey (SF-36), the Caregiver Strain Index (CSI) and the Modified Barthel Index (MBI).

Ascertainment of health

The Medical Outcomes Study 36-Item Short-Form Health Survey was used to measure general health and well being (Guyatt, et al.,1993; Stewart, et al.,1988; Testa & Simonson, 1996; Ware, et al., 1993). This is a generic, multidimensional, self-report health questionnaire (Ware, et al., 1993). The SF- 36 measures eight health concepts or domains: physical functioning, role limitation, bodily pain, general perception of health, energy-fatigue, social function, role limitation due to emotional problems,

and mental health. Each scale score ranges from 0 (worst health state) to 100 (best health state). The SF-36 has shown validity and internal consistency when used in general populations (Brazier, et al, 1992; Lyons, et al, 1994; McCallum, 1995; McHorney, et al, 1992; Sanson-Fisher, et al, 1998). Internal consistency reliability is high ($\alpha = 0.86$) and construct validity is supported by correlations with the physical and emotional health of the caregiver and with subjective views of the caregiving situation (Sullivan, 2004; Thornton, 2003).

Ascertainment of caregiving

The Caregiver Strain Index (CSI) is a tool that can be used to quickly identify families with potential caregiving concerns. It is a 13-question tool that measures strain related to care provision. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social and Time. Positive responses to seven or more items on the index indicate a greater level of strain. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an adult. Internal consistency reliability is high ($\alpha = 0.86$) and construct validity is supported by correlations with the physical and emotional health of the caregiver and with subjective views of the caregiving situation (Sullivan, 2004; Thornton, 2003).

Ascertainment of the adult child with CRS's functional ability

The Modified Barthel Index (MBI) was used to measure the deaf-blind adult child's functional ability. The MBI has shown to be valid and reliable for assessing disability (Kucukdeveci, et al., 2000; Shinar, et al., 1987). It contains 10 items with varying weights that score activities of daily living (ADL). The items bathing and grooming are scored 0 or 5; the items feeding, dressing, controlling bladder, controlling bowel, getting onto and off the toilet, and ascending and descending stairs are scored 0, 5, or 10. Items regarding moving from wheelchair to bed and walking on level surface are scored 0, 5, 10, or 15. The total MBI is a cumulative score of the 10 items, with a maximum score of 100 corresponding with complete independence, and a minimum score of 0 corresponding with total dependence. Celani et al., (2002) found that an MBI >90 (sensitivity 98%; specificity 97%) was a pivotal score for which patients did not require help from another person for everyday activities. Kay et al (1997) concluded that an MBI 80 (sensitivity 94%; specificity 80%) was the optimal cutoff score for self-reported dependency.

The MBI is primarily used as a record of what a patient does, not as a record of what a patient could do. The main aim is to establish the degree of independence from any help, physical or verbal, however minor and for

whatever reason. The MBI has been used in a variety of studies involving both acute and chronic disabilities. For example, although not comparable to the individual with CRS, a study assessing the management of Duchenne muscular dystrophy in young adults, found approximately 40% of their sample scored less than 50 points on the MBI (Meow-Keong Thong, et al., 2005). Another study evaluating the activities of daily living in patients with cerebral palsy found the MBI score was significantly lower in severe forms of the disability 16.9 ± 24.0 and quadriplegic types 14.8 ± 25.5 as compared with other disabilities (Lee, et al; 2004).

Statistical Analysis

To test the relationship between the independent and dependent variables, correlation and regression analysis was performed. The Pearson Correlation Coefficient factor was used to uncover the magnitude and significance of the relationship between the variables then a multivariate regression analysis was used to determine what the relationship between the variables are.

To assess the HRQOL (DV) the SF-36 structured self-reported scale, which evaluates eight domains of physical and mental health functioning with higher scores indicating better health, was used. The domains include: physical functioning, role limitation, bodily pain, general perception of health, energy fatigue, social function, role limitation due to emotional problems, and mental health. Each scale score ranges from 0 (worst health state) to 100 (best health state).

The results of this study are divided into internal and external factors which may predict maternal HRQOL. Internal factors are those unique to the care of the deaf-blind adult with CRS.

These include: method of communication (IV); behavior (IV); functional ability- assessed by using the MBI (IV) and maternal caregiver strain- assessed by using the CSI (IV). External factors are those which the literature has found to influence a HRQOL. These include: the residential status of the deaf-blind adult child with CRS the utilization of services, maternal financial status, maternal education, maternal years of caregiving, maternal marital status, number of children and birth order of children. This information was obtained via a self administered demographic questionnaire.

Results: Internal Factors

Communication between mother and adult deaf-blind child with CRS

- The communication method used between the mother and the deaf-blind adult child with CRS was significantly associated with the HRQOL domains (maternal SF36 total score).

- The more advanced method of communication between the mother and adult child with CRS, the higher the total score on the maternal SF36.
- The greatest comparison was between American Sign Language ($M = 80.39$, $SD = 20.8$) to gestures ($M = 31.49$, $SD = 32.57$), $F(8, 277) = 17.471$, $p < .001$.

Adult deaf-blind child with CRS's Behavior

- The deaf-blind adult child with CRS behaviors were significantly associated with the HRQOL domains (maternal SF36 total score).
- The more disruptive the adult child's behavior the lower maternal SF36 total score.
- The greatest comparison was between no apparent behavior ($M = 89.77$, $SD = 11.7$) to aggressive behavior ($M = 30.95$, $SD = 30.37$), $F(7, 279) = 21.130$, $p < .001$.

The deaf-blind adult child's functional ability-MBI

- The total MBI is a cumulative score with a maximum score of 100 corresponding with complete independence, and a minimum score of 0 corresponding with total dependence.
- The deaf-blind adult child with CRS functional ability (MBI) was significantly associated with the HRQOL domains (maternal SF36 total score): $F(22, 263) = 17.03$, $p < .001$ in the bivariate analysis.
- The MBI score indicated a positive relationship with a .51 point increase in the predicted HRQOL score in the multivariate analysis, holding all other variables constant. This was statistically significant $F(4, 280) = 222.327$, $p < .001$. (The higher the MBI score the more independent the child is resulting in a higher HRQOL score. The higher the HRQOL score the better the maternal health).

Maternal caregiver strain-CSI

- The Caregiver Strain Index (CSI) identifies families with potential caregiving concerns.
- Positive responses to seven or more items on the index indicate a greater level of strain.
- The maternal CSI scores were significantly associated in the bivariate analysis with the HRQOL domains (maternal SF36 total score): $F(13, 273) = 67.175$, $p < .001$.
- Multivariate analysis indicated a negative relationship: The CSI was associated with a – 4.6 point decrease in the predicted HRQOL score, holding all other variable constant.

This was statistically significant $F(4, 280) = 222.327$, $p < .001$. (A higher CSI score indicates more strain on the mother which is associated

with a lower HRQOL score. The lower the HRQOL score the poorer the health).

External Factors

The number of years the mother has cared for the adult deaf-blind child with CRS were significantly associated with the HRQOL domains (maternal SF36 total score). Additionally, with respect to the number of years, the regression coefficient for each year increase in caring would result in a 9.291 decrease in the HRQOL total score. This represents a negative association. The greatest comparison was between mothers providing care for 21-25 years ($M= 86.83$, $SD= 16.53$) to mothers providing care for more than forty years ($M= 30.74$, $SD= 29.27$), $F(8, 278) = 34.53$ $p < .001$.

Maternal marital status indicates a -1.0 point decrease in the predicted HRQOL score $F(4, 282) = 24.62$. This is not significant $p = .468$. Maternal education shows a 2.0 point increase in the predicted HRQOL score $F(5, 278) = 32.80$. This is not significant $p = .147$.

The number of children is associated with a 0.8 point increase in the predicted HRQOL score $F(7, 279) = 7.787$. This is not significant $p = .516$. Maternal financial status indicated a 4.9 point increase in the predicted HRQOL score $F(7, 279) = 20.48$. This is significant $p < .001$.

With regards to the utilization of services, case management was associated with a 1.5 point increase in the predicted HRQOL score $F(2, 267) = 144.46$. This was not significant $p = .632$. A job coach shows a .02 point increase in the predicted HRQOL score $F(3, 269) = 101.45$. This was not significant $p = .994$. Residential placement indicates a -3.1 point decrease in the predicted HRQOL score $F(2, 273) = 207.38$. This was not significant $p = .285$. Respite care shows a .92 point increase in the predicted HRQOL score $F(2, 267) = 206.94$. This was not significant $p = .69$. Transportation demonstrated a 2.5 point increase in the predicted HRQOL score $F(2, 279) = 104.736$. This was not significant $p = .396$. Medical care was associated with a -6.2 point decrease in the predicted HRQOL score $F(2, 282) = 72.896$. This was not significant $p = .262$. Dental care illustrated a -4.0 point decrease in the predicted HRQOL score $F(2, 281) = 122.807$. This was not significant $p = .434$. Occupational therapy has a 5.0 point increase in the predicted HRQOL score $F(2, 238) = 64.666$. This was not significant $p = .056$. Physical therapy demonstrated a 4.4 point increase in the predicted HRQOL score $F(2, 246) = 45.468$. This was not significant $p = .166$. Speech therapy shows a -5.2 point decrease in the predicted HRQOL score $F(2, 232) = 38.651$. This was not significant $p = .115$. Psychotherapy has a 6.5 point increase in the predicted HRQOL score $F(2, 256) = 139.323$. This was not significant $p = .022$. Behavioral intervention demonstrated a 1.5 point increase in the predicted HRQOL score $F(2, 270) = 142.614$.

This was not significant $p = .604$. Social Security Benefits has a 1.8 point increase in the predicted HRQOL score $F(2, 278) = 44.475$. This was not significant $p = .569$. Money for personal expenses demonstrated a 1.2 point decrease in the predicted HRQOL score $F(3, 275) = 86.541$. This was not significant $p = .71$. Telephone contact

Participants verbally answered all five questionnaire questions in the same manner as their written responses. The findings of the open ended question; “What is it like having a child with CRS?” provided viewpoints to consider when exploring the impact of caring for an adult child with CRS. Annotations were documented during the interview process and common concepts, principles, and themes were noted.

Four major themes emerged from this data:

- Maternal commitment: Many women in this study felt that they were the primary person responsible for the well-being of their handicapped child. This was true for both single (either due to divorce or widowed) mothers and women who lived with a spouse.
- Demanding physical care of the child with CRS: The demands of physically taking care of an adult deaf blind child with CRS were frequently discussed by mothers whose children live at home.
- Time management: The issue of time management also was repeated throughout the interview process. Descriptions such as “always running” and “taking longer to do everything” were frequently voiced.
- Maternal health implication of having a child with CRS: Throughout the interview process there was an expressed concern for maternal health. While a majority of the mothers felt that the decline in health was due to the aging process others believed that the physical demands of caring for a disabled child influenced their state of health.

Interestingly, some questioned if their health issues were due to contracting Rubella during pregnancy.

Discussion

Mothers who are caring for an adult child with CRS are faced with a multitude of challenges during the course of their child's life. Although caregiving is a normal part of being the parent of a young child, this role takes on an entirely different meaning when a child experiences functional limitations and possible long-term dependence as they age and become adults.

Caregivers of adult children with CRS have a dual role of caring for themselves and for their adult child whose self-care demands cannot be independently met.

This study identified variables within the caregiving process that involved a lower level of maternal caregiver strain. These include a higher

level of functional ability of the adult child with CRS, enhanced communication between the adult child with CRS and the mother, the absence of behavioral abnormalities and the utilization of services. At the other end of this spectrum, certain aspects in caring for the adult child with CRS involved a high level of strain. These include severe behavioral problems, lack of effective communication methods, not utilizing services and the adult child's complete physical dependence.

Limitations

Several limitations of this study are acknowledged. The volunteer nature of the sample makes it difficult to determine the exact population it represents and how those who chose not to participate may be different from those who do. Another limitation was the reliance on self report measures. Self-report is appropriate for many of the variables that involve individual perceptions. Still, it would be beneficial to include multiple perspectives in future studies when appropriate. Additionally, as with any other data collected by questionnaires, many of the findings are confined by the responses to pre-assumed conditions. In the questionnaire section addressing the utilization of services, many of the respondents selected "I don't know" or wrote additional comments along the margin in an attempt to clarify their answers. This was especially true in the areas of behavior and utilization of services. Perhaps a different format would have provided a more accurate representation of their utilization response.

A potential confounding factor within this study is the role of the adult deaf-blind child's intelligence quota (IQ) in relation to communication and functional ability. Vernon (2005) explains that the IQ assessment of deaf and hard of hearing individuals is often difficult to ascertain due to improper testing instruments. Because there are so many etiologies surrounding hearing impairments that affect cognition differently, there is no homogeneous population to perform a comparison study. Research has indicated that severely deaf individuals are language and socially deprived and since performance IQ tests are cognitive tasks, the level of language development may or may not be related to cognitive ability (Vernon, 2005). The results of this study indicate both the adult deaf-blind child's communication and functional ability influence the mother's HRQOL, however, the link between these variables may not be direct but rather mediated by some other factor such as the child's IQ.

Conclusion

Recommendations for Future Research

The results of this study have important implications for future research as well as for interventions with maternal caregivers. Understanding

which characteristics of adult handicapped children contribute most significantly to problems experienced by the mother may be extremely valuable to professionals interested in helping families address these problems.

There is a great need for continued research in the area of IQ as it relates to deaf-blindness and more specifically, CRS. Most conventional assessment tools have not been designed or have the capacity to comprehensively assess individuals with dual sensory loss and multiple disabilities.

With deafblindness, individuals may be unable to see and hear instructions adequately and assessment tools that have clinical terminology may not be able to be directly translated into sign language. A range of clinical assessment tools partially adapted to suit people with deafblindness, in combination with observation and qualitative and quantitative data gathered over an extended time period might offer an area for further investigation. Because social support practices utilize many services, including health care, more needs to be known about how families, especially mothers, of adult children with special needs use these professional social support services. Areas such as barriers and incentives to utilization need further exploration.

The findings of the open ended question; “What is it like having a child with CRS?” provided viewpoints to consider when exploring the impact of caring for an adult child with CRS. More extensive data needs to be collected by interview instead of self administered questionnaires.

This would provide a richer perspective to validate or explicate portions of this study. Additionally, by interviewing these mothers, study participants would be better able to fully describe the actual experience without pre-set limitations.

Recommendation for practice, policy and education

The results of this study have implications for practice, policy and education. As women who have been the primary caregivers of their children with CRS increase in age, the predictors of maternal HRQOL become increasingly more important. It is imperative for health care providers to assess the health condition of caregivers in both the hospital and community settings whenever possible, to ensure that the challenges of caring will not cause them to become the second patient instead of the caregiver (Sit et al., 2004).

The number of years of caregiving was one variable most highly related to a significant decrease in the maternal HRQOL. Interventions may assist mothers of dependent adult children with late life caregiving responsibilities. One method to intervene might be to expand the available

respite care alternatives available or increase the utilization of support services.

Certain findings have particular implications for early intervention services to families of children with disability. The importance of communication, behavior and independence in activities of daily living skills in relation to maternal HRQOL suggests the need for greater focus on education, physical support and counseling assistance for both the disabled individual and the caregiver. The results also indicate the need for health care providers to be aware of and try to intervene before detrimental effects from stressful events in the lives of caregivers and from the day to day problems faced by mothers of the most severely disabled children occur.

The results of this study point to factors which influence maternal HRQOL. Successful intervention needs to address those factors identified as predictors of maternal HRQOL and provide services which are easily accessible to parents. The difficulties in obtaining access to and information about these services were voiced in interviews with this group of mothers. To quote one mother from Iowa: "Once my son reached his twenty-first birthday, all support stopped. He was too old for school programs and no longer entitled to intervention services. Every day I have to fight the state for help." A study by Sen and Yurtsever (2007) found that a majority of parents (81.5%) of disabled children want support and information but have difficulty acquiring it. More than half the families wanted information and counseling about their child's condition but found that the professionals provided insufficient support. Since each caregiver's situation is unique, it is important for health care providers to plan strategies for the needs of caregivers, make caregivers consciously aware of these strategies and implement and evaluate the plan to meet those needs. The caregivers' social network should be continuously assessed throughout the caregiving process. If support is lacking, health care providers can direct caregivers to the appropriate services. More resources are needed to support these families caring for adult disabled children at home. In addition, adult care alternatives need to be available when families are no longer able to care for this population. Furthermore, a full range of educational alternatives should be considered for funding and made available for adult disabled children.

Summary and Conclusion

Although rubella and new cases of congenital rubella syndrome are no longer a problem in the United States, currently, there are 10.2 million children with special health care needs (National Data Resource Center, 2008). In a time in which more parents are being encouraged to care for their disabled children in their homes, recognizing factors that influence maternal HRQOL and developing ways to assist them as they cope with added

burdens, as these children age, could well be among the most useful ways of helping these families.

As the prevalence of children with disabilities continues to increase, so does the demand for health care professionals who understand the unique needs of their caregivers. As these children transition to adult care, health care professionals must understand the impact the special needs have on the mother and by extension, the family, and be able to provide the care and resources needed to bridge the transition and support the continued care.

The importance of a full understanding of the predictors that impact a mother's health related quality of life cannot be overemphasized. Although this study made a contribution to the understanding of this area and ideally to the interventions that can actually improve one's life, more is needed.

The data presented in this study, identifies key factors affecting maternal health and wellbeing as it relates to the practical day-to-day needs of mothers caring for an adult deaf-blind child with CRS. Since CRS is often associated with a broad spectrum of disabilities that most often lead to some degree of dependence for self-care, mobility, and communication, it is thought that these findings could be cautiously generalized to mothers of children with other intellectual and physical disability. According to the National Data Resource Center for Child and Adolescent Health (2006), 1 in 5 American households with children have at least one child with a chronic or disabling health condition. Currently, 10.2 million children in the US are considered to have special health care needs (SHCN) (US Department of Health and Human Services, Maternal and Child Health Bureau, 2004). As increasing number of children with SHCN transition to adult care, health care professionals must understand the impact these special needs has on the child and family and be able to bridge that transition.

The data derived from this study is significant for health care professionals who work with caregivers and more specifically, mothers of children with disabilities. Health care professionals are in a position to assess, counsel and provide resources to caregivers before these predictors progress to emotional and physical illness. As the prevalence of children with disabilities continues to increase (Merrick & Carmeli, 2003), so does the demand for health care providers who understand the unique physical, psychosocial and caregiving needs.

Lastly, as further research is conducted, the information provided could potentially enable health care providers to tailor intervention and education strategies in order to better assist the growing number of families who take on the role of caring for a child with a disability. As these mothers take on a lifetime of caring for their children, health related quality of life issues become ever more important. This study has drawn attention to factors influencing the HRQOL of mothers caring for adult deaf blind children with

CRS. Several mothers in this study were acutely aware that their caregiving experience could have been worse. As one mother reflected, "I survived thanks to a solid, flexible marriage, professional experience dealing with disability issues, no behavior problems, and enough income to manage on reduced work hours. Not everyone with a CRS child has these things going for them. I have no idea how some mothers continue to survive." Yet, these mothers do continue to survive and struggle to persist in caring for their child with CRS on a daily basis. Proactive involvement by health care professionals, including routine contact with these mothers and appropriate support referrals has the possibility of significantly reducing the extent of caregiving difficulties while enhancing the quality and cost effectiveness of care. Finally, continued research among mothers of disabled children and adults may provide additional insights into how individuals, families, and communities adapt to ever-changing caregiving demands.

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